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**Promotion and protection of human rights: human rights questions, including alternative approaches for improving the effective enjoyment of human rights and fundamental freedoms**

# Enjoyment of human rights by persons with albinism

## Note by the Secretary-General

The Secretary-General has the honour to transmit to the General Assembly the report of the Independent Expert on the enjoyment of human rights by persons with albinism, Ikponwosa Ero, in accordance with Human Rights Council resolutions 28/6 and 37/5.

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# Report of the Independent Expert on the enjoyment of human rights by persons with albinism

*Summary*

In the present report, the Independent Expert on the enjoyment of human rights by persons with albinism focuses on the central pledge of the 2030 Agenda for Sustainable Development to leave no one behind, beginning with those furthest behind. She asserts that because persons with albinism are, in many parts of world, among the poorest and most marginalized and they are often excluded from public policies for key sectors such as health and education, this imperative applies to them. The Independent Expert affirms that the pledge contains a transformative element that implies building bridges to reach those left furthest behind. It is proposed that these bridges include specific measures, which correspond to the Sustainable Development Goals and at the same time address the issues facing persons with albinism. Such measures will turn the central pledge of the 2030 Agenda into reality and, as a consequence, accelerate the attainment of the Goals.

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# I. Introduction

1. The mandate of the Independent Expert on the enjoyment of human rights by persons with albinism was established by the Human Rights Council in its resolution 28/6 in 2015 and subsequently extended in resolution 37/5 in 2018. The current mandate holder, Ikponwosa Ero, submitted her first and second report to the General Assembly in 2016 and 2017, respectively. The first report (A/71/255) was a preliminary survey on the root causes of attacks and discrimination against persons with albinism and the second report (A/72/131) was a review of the applicable international human rights standards and related obligations addressing the issues faced by persons with albinism.

2. The 2030 Agenda for Sustainable Development is instrumental to achieving the enjoyment of human rights by persons with albinism worldwide. This is because the 2030 Agenda is aimed at leaving no one behind, beginning with those furthest behind. Persons with albinism represent a relatively small segment of the population across the globe and are disproportionately affected by poverty, mainly in developing countries and least developed countries. Moreover, they face multiple and intersecting forms of discrimination on the grounds of disability and colour and are often excluded from public policies in the key areas of health and education.

3. Persons with albinism are, therefore, among the groups that should be given priority attention in the implementation of the 2030 Agenda. Such attention can be attained by both the broad Goals and the targets of the 2030 Agenda and supplemental measures developed specifically for such groups, including persons with albinism, at the national, regional and/or international levels. These supplemental measures should specifically address particular issues faced by persons with albinism. The measures should be linked to the Goals, targets and indicators, as well as the implementation, review and follow-up framework, of the 2030 Agenda. Support for such measures would accelerate the realization of the pledge to leave no one behind, beginning with those furthest behind, while simultaneously accelerating overall progress towards sustainable development.

## A. Condition of albinism

4. Albinism is a relatively rare, non-contagious, genetically inherited condition that affects people regardless of race, ethnicity or gender. For a person to be affected by albinism, both parents must carry the gene and, in that case, there is a 25 per cent chance, in each pregnancy, that their child will be born with albinism. The condition is characterized by a significant deficit in the production of melanin, which results in the partial or complete absence of pigment in any part or all of the skin, hair and eyes.

5. Persons with albinism are found across the globe, but their proportion vis-à-vis the larger population varies by region. While thorough and reliable research remains necessary to determine accurate proportions worldwide, estimates indicate that 1 in 17,000 to 20,000 people are affected by oculocutaneous albinism in North America and Europe, while in sub-Saharan Africa the occurrence varies from 1 in 5,000 to 1 in 15,000, with certain groups reporting frequencies as high as 1 in 1,000. Other studies suggest that, in specific groups in Panama or in the Pacific region, the rate of people affected could be as high as 1 in 70 and 1 in 125, respectively (see A/HRC/31/63, para. 12).

6. Albinism often results in two congenital and permanent health conditions: visual impairment to varying degrees and high vulnerability to skin damage from ultraviolet rays, in particular skin cancer. In addition to health issues, persons with albinism face several convergent challenges in terms of social development, such as barriers in

access to education, employment and social services and in particular barriers in access to vision services and services relating to skin cancer prevention and treatment (see A/72/169, paras. 28–32 and 35–50). Persons with albinism are highly vulnerable to skin cancer, a primary factor in their early mortality in several countries. In some countries, it is reported that a majority of persons with albinism die from skin cancer between 30 and 40 years of age (see A/HRC/37/57, para. 36).

7. Worldwide, persons with albinism suffer from discrimination and stigmatization. In 28 countries in sub-Saharan Africa, they face specific challenges centred on witchcraft-related harmful practices, including physical attacks, killing, maiming, rape, grave robbery, trafficking in persons and trafficking in body parts. Specific focus and studies on trafficking in body parts are necessary beyond the present report as the practice differs from trafficking in persons, which typically does not cover the removal of and/or trade in body parts of humans other than organs.

## B. International legal framework and awareness

8. Persons with albinism are entitled to civil, political, economic, social and cultural rights recognized in international human rights law. Of particular importance are the International Convention on the Elimination of All Forms of Racial Discrimination and the Convention on the Rights of Persons with Disabilities, both of which provide protection against discrimination. The latter is particularly important regarding reasonable accommodation for persons with albinism, owing to their vision impairment and the need for preventive measures regarding skin cancer. In addition, the Convention on the Elimination of All Forms of Discrimination against Women and the Convention on the Rights of the Child recognize the need for protection measures for women and children with albinism (see CRC/C/CMR/CO/3-5), who are disproportionately affected by poverty and remain highly vulnerable to various forms of violence, including, but not limited to, witchcraft-related harmful practices.

9. In 2013, the international community expressed concern regarding attacks against persons with albinism, including women and children, stating that the attacks were often committed with impunity. They also raised concern at the widespread discrimination, stigma and social exclusion suffered by persons with albinism. In 2014, less than a year before the adoption of the 2030 Agenda, the General Assembly proclaimed 13 June as International Albinism Awareness Day (see General Assembly resolution 69/170), calling for increased awareness and understanding of albinism in order to combat global discrimination against and stigmatization of persons with albinism. In 2018, the Secretary-General declared that the Day was "an opportunity to declare solidarity with people with albinism and strive together so those who are often left furthest behind are able to live free from discrimination and fear, and empowered to enjoy their full human rights".[1]

# II. Leaving no one behind

## A. International commitment

10. In 2015, the international community developed the 2030 Agenda to guide and spur sustainable development for the following 15 years. In doing so, it pledged that in carrying out the Agenda, no one would be left behind, reaching those furthest behind first (see General Assembly resolution 70/1, para. 4). The 2030 Agenda

[1] See www.un.org/sg/en/content/sg/statement/2018-06-13/secretary-generals-message-international-albinism-awareness-day.

represents an international commitment towards achieving equality and non-discrimination within every society by focusing on discriminated groups.[2] It places respect for human rights at the core of its vision, including respect for equality and non-discrimination (ibid., para. 18).

11. In addition, the overarching imperative of leaving no one behind is firmly anchored in the 17 Sustainable Development Goals, with "numerous goals and targets [including] a focus on inequalities and advancement of communities that have historically experienced discrimination".[3]

12. Moreover, the follow-up and review process of the implementation of the 2030 Agenda "will be people-centred, gender-sensitive, respect human rights and have a particular focus on the poorest, most vulnerable and those furthest behind" (see General Assembly resolution 70/1, para. 74 (e)). This is particularly important in tracking progress towards the achievement of the Sustainable Development Goals, notably through the 230 indicators (see E/CN.3/2016/2/Rev.1, annex IV).

## B. Rationale: continuity and transformation

13. The objective of leaving no one behind includes a core aim of ending absolute poverty and discrimination by prioritizing and fast-tracking action for those furthest behind. It means that affirmative action should be taken to ensure that "populations at risk of being left behind are included from the start" and requires "enabling people and groups who are left behind to progress at a higher rate than those who are better off".[4] The 2030 Agenda and the Goals therein are a continuation of the Millennium Development Goals, and through the pledge to leave no one behind, beginning with those furthest behind, it also has the overarching purpose of transformation towards substantive equality for all.

14. Regarding the Millennium Development Goals, many of them targeted only a percentage of the mainstream population and progress was measured with averages, instead of disaggregated indicators.[5] Consequently, inequalities affecting specific groups were neither measured nor addressed, even though the situation of many of the groups was deteriorating.[6] Therefore, the pledge to leave no one behind responds to lessons learned from those Millennium Development Goals, as well as to demands made during the consultation on the 2030 Agenda to address all forms of inequalities as a matter of priority.[7]

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[2] Women and girls, pregnant women, newborns, unemployed persons, children in vulnerable situations, family farmers, indigenous peoples, pastoralists and fishers, persons with disabilities, migrant workers, work-injury victims, youth and older persons; and those in vulnerable situations, marginalized communities and the poor.

[3] Inga T. Winkler and Margaret L. Satterthwaite, "Leaving no one behind? Persistent inequalities in the SDGs", *International Journal of Human Rights*, vol. 21, No. 8 (2017).

[4] Elizabeth Stuart and Emma Samman, "Defining 'leave no one behind'", Overseas Development Institute briefing note (October 2017), pp. 2–3.

[5] Dan Seymour, "Integrating human rights and equality: a development agenda for the future", *in* Malcolm Langford, Andy Sumner and Alicia Ely Yamin, eds., *The Millennium Development Goals and Human Rights: Past, Present and Future* (New York, Cambridge University Press, 2013).

[6] Stuart and Samman, "Defining 'leave no one behind'", p. 2.

[7] See United Nations, "Summary of the Stakeholder Preparatory Forum for the post-2015 development agenda negotiations", paper prepared for the forum, New York, January 2015, and the "Final compilation of amendments to goals and targets by major groups and other stakeholders including citizen's responses to My World 6 priorities", prepared for the thirteenth session of the Open Working Group on Sustainable Development Goals, New York, July 2014.

15. Consequently, the 2030 Agenda is explicitly grounded in human rights by stating that the Sustainable Development Goals seek to realize the human rights of all (see General Assembly resolution 70/1, preamble and paras. 8, 10, 18 and 19). People-centred, universal and indivisible, the 2030 Agenda promotes equality and non-discrimination, participation and accountability. It also reaffirms the importance of the international human rights obligations of Member States.

16. In paragraph 19 of General Assembly resolution 70/1, it is stated:

> We reaffirm the importance of the Universal Declaration of Human Rights, as well as other international instruments relating to human rights and international law. We emphasize the responsibilities of all States, in conformity with the Charter of the United Nations, to respect, protect and promote human rights and fundamental freedoms for all, without distinction of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth, disability or other status.

## C. Scope: universality and affirmative action

17. Fundamentally, leaving no one behind seeks the effective implementation of the right to equality and non-discrimination, which is both intrinsic and instrumental to sustainable development.[8] The related international human rights obligations require the adoption of specific measures[9] to ensure the realization of the rights of persons with disabilities and measures of affirmative action to address discrimination.[10] In this regard, the adoption of specific measures for persons with albinism, a constituency of persons with disabilities with intersecting experiences of discrimination based on colour and/or appearance, as well as gender, among other things, is in line with international human rights standards and obligations and is instrumental in the universal pledge of leaving no one behind, beginning with those furthest behind.

18. The scope of the 2030 Agenda is universal. It concerns all Member States and aims to reach everyone. Consequently, to be truly universal, the crucial challenge is to identify those who are left behind and, among them, those who are the furthest behind. To do so, an analysis of levels of deprivation should be combined with the characteristics or the status of these populations, with a special attention to intersectionality, as it amplifies the experience of deprivation.[11]

19. The 2030 Agenda and related Sustainable Development Goals, targets and indicators include explicit references to certain groups. Of direct relevance to persons with albinism are seven targets referring to persons with disabilities in the areas of gender equality in education and accessible schools (targets 4.5 and 4.A), employment (target 8.5), inclusion and empowerment (target 10.2), accessible transport (target 11.2), accessible public spaces (target 11.7) and data disaggregation (target 17.18). In addition, 11 indicators require disaggregation by disability, all related to the above targets, except on social protection (indicator 1.3.1) and participation in decision-making (indicators 16.7.1 and 16.7.2). These latter

[8] Office of the United Nations High Commissioner for Human Rights (OHCHR), "Human rights and poverty reduction: a conceptual framework" (HR/PUB/04/01).

[9] See Convention on the Rights of Persons with Disabilities, art. 5 (4).

[10] Committee on the Elimination of Racial Discrimination, general comment No. 32 (2009) on the meaning and scope of special measures in the Convention, and Committee on the Elimination of Discrimination against Women, general recommendation No. 25.

[11] Stuart and Samman, "Defining 'leave no one behind'", p. 3.

indicators require data disaggregated by disability that are not explicitly mentioned in their related targets (indicators 1.3 and 16.7).

20. Persons with albinism are subject to various forms of discrimination based on the characteristic of colour; this discrimination should be captured by data disaggregated by race. In this regard, only two targets refer to disaggregation by race, namely those on equality and data collection (targets 10.2 and 17.18). The associated indicators do not account for race.

### D. Implementation: priority and fast-tracking

21. Worldwide, persons with albinism are among those who have been left behind and often are among the furthest behind. Accordingly, Member States and relevant stakeholders are expected to prioritize and fast-track affirmative action for persons with albinism in the implementation of the Goals, including in the context of national, regional and global follow-up and review processes.

22. Highest priority must be given to persons with albinism in sub-Saharan Africa, considering the urgent need to eradicate witchcraft-related harmful practices. Moreover, because these are countries with high sun exposure, the threat of skin cancer should be addressed as a high-priority matter of public health.

23. In national settings, specific and detailed demographic and socioeconomic data by country on persons with albinism are lacking. This challenge must be addressed as a priority. In this regard, the Secretary-General has stated that "further work is needed to enhance the coverage, quality and frequency of data to ensure that the most vulnerable and marginalized people are the first to be reached" (see E/2016/75, para. 134).

24. Disaggregated data on national populations are essential to "demonstrate the existence, magnitude and interplay of multiple forms of inequalities" and to identify the most marginalized persons.[12] Collecting disaggregated data is therefore essential to ensuring that all groups, notably those characterized by intersecting discrimination, and their needs, are made visible in national statistics, especially a relatively small and often widely dispersed group such as persons with albinism.

25. It is therefore essential to collect data on persons with albinism and their contextual characteristics, including their socioeconomic situation regarding housing, health, education and employment. The fundamental characteristics are the combination of disability (lack of reasonable accommodation for visual impairment and high vulnerability to skin cancer) and a spectrum of discrimination (and harm) based on skin, hair and eye colour. As a corollary, relevant Goals, targets and indicators provide the framework of how the 2030 Agenda and its processes could effectively contribute to the enjoyment of human rights by persons with albinism, and by extension, any group left behind.

## III. Relevant Sustainable Development Goals and related specific measures for persons with albinism

26. Of direct relevance for persons with albinism are Goal 1, on ending poverty, particularly for persons living in low- or middle-income countries, Goal 3, on health, Goal 4, on education, Goal 5, on gender equality, Goal 8 on employment and decent work, Goal 10, on reducing inequalities, Goal 16, on peaceful societies and access to justice and Goal 17, on the implementation, follow-up and review of the Goals, as

[12] Winkler and Satterthwaite, "Leaving no one behind?", p. 1073.

well as data collection. Other Goals also contribute to the enjoyment of the right to an adequate standard of living, which is of general relevance to persons with albinism. Those include Goals 2, 6, 7 and 11, on food, water, cities and energy, respectively.

27. All these areas are crucial for improving the living conditions of persons with albinism, as they relate to specific vulnerabilities stemming from the unique intersection of characteristics at the core of the condition of albinism.

28. The relevant Goals and targets need to be contextualized to the realities and challenges faced by persons with albinism, notably by indicators that provide disaggregate data. This could be achieved through the adoption of specific measures to ensure that efforts to achieve the Goals are not excluding persons with albinism, as that would be in contradiction to the pledge to leave no one behind. In other words, specific measures would be the bridge between the 2030 Agenda and marginalized and vulnerable groups. Specific measures, such as those mentioned below, would not merely complement the Goals but would also bring the marginalized into the fold of the 2030 Agenda and, most importantly, catalyse and actualize its transformative aspiration while facilitating the overall objective of reaching all persons.

## A. Right to an adequate standard of living

### Ending poverty in all its forms everywhere

29. Persons with albinism are more likely to experience social exclusion and poverty owing to the discrimination and stigmatization that they face. In some countries, the stigma also affects their families, further hindering their socioeconomic opportunities. In low-income countries, the limited and uneven provision of public services in the critical areas of health, education, social security and security disproportionately affects persons with albinism (see A/72/169).

*Relevant Goals*

30. Goal 1, ending poverty in all its forms everywhere, is crucial for the enjoyment of human rights by persons with albinism. It calls for the national implementation of appropriate social protection systems and measures for all, including floors, and by 2030 to achieve substantial coverage of the poor and the vulnerable (target 1.3).

31. The related indicator will measure the proportion of the population covered by social protection floors/systems, by sex, distinguishing children, unemployed persons, older persons, persons with disabilities, pregnant women, newborns, work-injury victims and the poor and the vulnerable (indicator 1.3.1). The indicator aims at achieving substantial coverage of the poor and the vulnerable, meaning that efforts need to include persons with albinism and prioritize action directed at them. In this regard, the measure of progress should be the number and proportion of persons with albinism covered by social protection and welfare schemes.

*Specific measures*

32. As part of specific measures complementary to the Goals regarding the right to an adequate standard of living, a specific measure could be put in place regarding social protection for persons with albinism. The specific measures could include measures to educate all persons with albinism and their family members on existing national and local social protection and social welfare schemes for which they may be eligible. Accordingly, the number of persons with albinism who have received tailored education on social protection and social welfare schemes and who have benefited from such protection would serve as a measure of progress.

33. Regarding attacks against persons with albinism in some countries, specific support for victims is required, such as psychosocial and rehabilitation programmes based on legal and policy frameworks for long-term support. Such support could be part of the national social protection system and be measured by: (a) the proportion of victims, including families, receiving adequate socioeconomic and legal support; and (b) the number of countries with a legal and policy framework for long-term support services for victims and their families.

**Health**

34. The high vulnerability to skin cancer of persons with albinism is the most pressing health issue worldwide. The risk of developing skin cancer is about 60 times less for persons with dark skin than for persons with fair skin. In regions close to the equator, the need for preventive and curative measures relating to skin cancer is a priority. In sub-Saharan Africa, studies show that skin cancer is the major cause of mortality of persons with albinism and severely limits their life expectancy.[13]

35. Furthermore, the condition of albinism in nearly all cases implies vision impairment resulting from refractive (myopia, hyperopia and astigmatism) and non-refractive (notably nystagmus, photophobia and strabismus) impairments. In low-income countries, low availability and use of adaptive devices for vision by persons with albinism is reported.[14]

*Relevant Goal*

36. Goal 3, to ensure healthy lives and promote well-being for all at all ages, is a priority for persons with albinism. Specifically relevant are targets 3.4 and 3.8. Target 3.4 is, by 2030, to reduce by one third premature mortality from non-communicable diseases through prevention and treatment and to promote mental health and well-being. In addition, target 3.8 aims at achieving universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all. The indicator of progress for the former is the mortality rate attributed to cancer, among other diseases (target 3.4.1), while for the latter it is the coverage of essential health services, which, inter alia, includes interventions among the general and the most disadvantaged populations (target 3.8.1).

*Specific measures*

37. Among specific measures complementary to the Goals, those regarding persons with albinism include training health-care workers on issues relevant to the human rights of persons with albinism. Progress towards this complementary target can be measured by: (a) the number of countries with a legal, policy and institutional framework for human rights education and medical education on albinism in the health sector; (b) the proportion of health-care workers trained on albinism nationally; and (c) the accuracy of content and pedagogy of training curricula.

38. It is of utmost importance that Goal 3 include specific measures for providing sunscreen as an essential medicine or item for persons with albinism in order to prevent the devastating effects of skin cancer on this population. Another specific complementary target could include national assessments of locally produced

[13] Patricia M. Lund and Mark Roberts, "Prevalence and population genetics of albinism: surveys in Zimbabwe, Namibia, and Tanzania", in Jennifer Kromberg and Prashiela Manga, *Albinism in Africa: Historical, Geographical, Medical, Genetic, and Psychosocial Aspects* (London, Academic Press, 2018).

[14] Nnenma N. Udeh and others, "Oculocutaneous albinism: identifying and overcoming barriers to vision care in a Nigerian population", *Journal of Community Health*, vol. 39, No. 3 (June 2014).

sunscreen and, wherever feasible, the launching of local production to guarantee quality, accessibility and availability and reduce mortality rates from skin cancer. Beginning with those furthest behind, Member States and all stakeholders could give priority to this target regarding persons with albinism. Corresponding indicators of progress could include: (a) the proportion of persons with albinism, disaggregated by age and gender, who have adequate and sufficient access to sunscreen and similar dermatological products obtained at no cost in each country; and (b) the number of countries that have removed import taxes on all low-vision devices. The latter is essential to ensure not only accessibility and affordability, but also reasonable accommodation.

**Education**

39. Children with albinism, in particular girls, encounter several challenges in gaining access to education, including high dropout rates and low educational attainment (see A/72/169, paras. 35–38). This is due to a lack of reasonable accommodation for, and awareness about, the condition of albinism, in combination with stigmatization, lack of acceptance, ostracism and loss of self-esteem fuelled by misbeliefs about albinism. In addition, in the wake of attacks in some countries, families are seeking to protect their children with albinism by keeping them at home.

*Relevant Goal*

40. Goal 4, to ensure inclusive and equitable quality education and promote lifelong opportunities for all, could be a priority for persons with albinism. Targets 4.5, 4.7 and 4.A are also of direct relevance. Target 4.5 seeks, by 2030, to eliminate gender disparities in education and ensure equal access to all levels of education and vocational training for the vulnerable, including persons with disabilities, indigenous peoples and children in vulnerable situations.

41. Target 4.7 seeks to ensure that all learners acquire the knowledge and skills needed to promote sustainable development, including, through human rights and the promotion of a culture of peace and non-violence. This target can greatly contribute to ensuring awareness of albinism and respect for persons with albinism through human rights education throughout the education system, in particular in national education policies, curricula, teacher education and student assessment, as set out in indicator 4.7.1. The complementary target 4.A aims at building and upgrading education facilities that are child, disability and gender sensitive and providing safe, non-violent, inclusive and effective learning environments for all, notably through adapted infrastructure and materials for students with disabilities, as included in indicator 4.A.1.

42. Targets 4.5 and 4.7 could, therefore, help eliminate discrimination against children with albinism in the education system, promote gender equality and ensure reasonable accommodation for their visual impairment and skin vulnerability, as their situation is given priority and related indicators are disaggregated to account for persons with albinism.

*Specific measures*

43. As part of specific measures complementary to the above-mentioned Goal and targets concerning persons with albinism, a specific measure could ensure that reasonable accommodation is made available at all levels of education for persons with albinism. In this regard, Member States could include the development and incorporation of pre-existing guides on students with albinism into teacher-training curricula in their national plans and policies in order to meet target 4.5.

44. In addition, the training of teachers and educators on albinism and how to provide reasonable accommodation for pupils could be a core element in achieving Goal 4. Such training could be monitored through two key indicators: (a) the proportion of pupils with albinism enjoying reasonable accommodation at school in each country; and (b) the proportion of teachers and educators trained on providing reasonable accommodation for children with albinism in each country. With regard to reasonable accommodation, low-vision devices should be available and accessible at no cost, including by removing import taxes. Furthermore, the provision and adequate use of sunscreen at all educational levels, especially in primary and secondary schools, could be included as a component of target 4.5.

**Full employment and decent work**

45. Goal 8 seeks to promote sustained, inclusive and sustainable economic growth, full and productive employment and decent work for all, which is one of the challenges faced by persons with albinism owing to discrimination, a lack of reasonable accommodation in the workplace and a lack of security in parts of sub-Saharan Africa. Accordingly, access to indoor work and related vocational training is fundamental for persons with albinism, which also requires raising awareness among employers (see A/72/169, paras. 39–42).

*Relevant Goal*

46. Target 8.5 is of particular relevance since it aims at achieving, by 2030, full and productive employment and decent work for all, including for young people and persons with disabilities, as well as equal pay for work of equal value. Indicators 8.5.1 and 8.5.2 regarding average hourly earnings and unemployment rates require disaggregated data to account for persons with disabilities.

47. Consequently, Goal 8 and related targets 8.5 and 8.8, could also aim at significantly increasing the number of persons with albinism enjoying decent work in safe and healthy conditions, with equal pay for work of equal value, with progress measured through: (a) average hourly earnings of female and male employees, by occupation, age and disability, including albinism; and (b) unemployment rate of persons with albinism.

48. Regarding decent work, target 8.8 relates to the protection of labour rights and a safe and secure working environment. Indicator 8.8.2, on the increase in national compliance in respect of labour rights, could be complemented by an indicator measuring the proportion of persons with albinism with jobs, whether indoor or with adequate protection against the sun, as well as reasonable accommodation including through safeguards for self-protection against attacks.

## B. Peaceful societies and access to justice

49. In many aspects, the enjoyment of human rights by persons with albinism requires peaceful societies in which discrimination has been overcome, particularly in countries in which myths and witchcraft-related harmful practices lead to attacks, maiming, killings and grave robbery. Victims of discrimination and violence in this context are primarily women and children with albinism. Families and mothers of children with albinism also tend to be victims of discrimination by association.

50. Regarding access to justice, persons with albinism face discrimination in all regions, although to varying degrees, without redress. Obstacles in access to legal protection and remedies have been systematically reported. In the instances of attacks

against persons with albinism, there is a pattern reflecting widespread impunity.[15] Too often, only middlemen and hired hands — and not the masterminds — are arrested or prosecuted.[16]

*Relevant Goal*

51. Goal 16, to promote peaceful and inclusive societies for sustainable development, free from all forms of discrimination, is of utmost importance to persons with albinism worldwide. In this regard, several targets and indicators related to Goal 16 are directly relevant, such as the significant reduction of all forms of violence and related death rates everywhere (target 16.1), ending abuse, exploitation, trafficking and all forms of violence against and torture of children (target 16.2), the promotion of the rule of law at the national and international levels and ensuring equal access to justice for all (target 16.3), ensuring responsive, inclusive, participatory and representative decision-making at all levels (target 16.7) and ensuring public access to information and protection of fundamental freedoms, in accordance with national legislation and international agreements (target 16.10). Lastly, the promotion and enforcement of non-discriminatory laws and policies for sustainable development is also relevant (target 16.B).

52. The objective of reducing all forms of violence and related deaths should cover all forms of violence perpetrated against persons with albinism. Indicators of progress include the number of intentional homicides (indicator 16.1.1), the number of conflict-related deaths (indicator 16.1.2), incidents of physical, psychological or sexual violence (indicator 16.1.3) and the feeling of safety among the population when walking alone around the area of livelihood (indicator 16.1.4). All these indicators are particularly relevant to measuring progress in curbing attacks against persons with albinism and could provide a wealth of information, as long as the data are specifically disaggregated by persons with albinism.

*Specific measures*

53. The following proposed supplementary measures could be adopted to ensure that persons with albinism are duly taken into account: (a) conduct national needs assessments (including security and reintegration) of persons with albinism; (b) ensure full access to police and other security apparatus at the community level; (c) provide security goods to persons with albinism in all areas in which attacks are occurring and to those who have been victims of attacks; and (d) safely reintegrate persons with albinism who have been displaced by attacks and stigmatization.

54. The indicators of achievement of the proposed specific measures include: (a) the number of needs assessments completed; (b) the extent of consultation with and participation of persons with albinism in the process; (c) the proportion, by country, of persons with albinism who feel safe walking around the area in which they live; (d) the number of relevant communities with improved, sufficient and adequate police presence and protection in each country; (e) the number of persons with albinism and their families who have received security goods for their effective protection and the proportion of the population with albinism that they represent; and (f) the area covered by the delivery of security goods where there have been or there are numerous attacks.

[15] See A/HRC/28/75, A/HRC/37/57/Add.1, A/HRC/34/59/Add.1 and A/HRC/34/59/Add.2.

[16] Office of the United Nations High Commissioner for Refugees, "United Nations rights expert welcomes conviction of mastermind in murder of woman with albinism", 3 March 2017.

55. Victims of attacks are primarily children with albinism,[17] owing to their high vulnerability; target 16.2 could contribute to ending violence against them. Related indicators could focus on: (a) violence by caregivers, which is relevant to reported cases implicating family members in attacks against persons with albinism (indicator 16.2.1); (b) trafficking in persons, which should encompass the related but distinct offence of trafficking in body parts of persons with albinism (indicator 16.2.2); and (c) sexual violence, which should specifically record cases against persons with albinism, as the motive behind such acts is often linked to the mistaken belief in an alleged curative effect for HIV infection (indicator 16.2.3). Supplementary policies and measures to be taken to achieve targets 16.1 and 16.2 could include, for countries with records of attacks, accurate documentation and publication of information on every attack and government action taken on them, which can be measured by: (a) the number of regular reports and other official publications of credible and reliable quality on documentation of attacks and government actions; and (b) the number of reports made public through official sites, the media or another type of publication or dissemination activity.

56. In this regard, target 16.10, to ensure public access to information and protect fundamental freedoms could be considered closely related to the following supplemental indicators: (a) the number of verified cases of violence against persons with albinism who are human rights advocates (indicator 16.10.1); and (b) the number of countries that have adopted and implemented constitutional, statutory and/or policy guarantees for public access to information (indicator 16.10.2).

57. In addition, to measure progress with regard to of effective rule of law and equal access to justice (target 16.3), the following supplemental measure could be considered regarding persons with albinism: fully investigate and prosecute all reported cases, including the prosecution of masterminds of attacks and related violations. This would be measured through the number and proportion of prosecutions completed, including where masterminds are prosecuted, in each country in which attacks have been reported.

58. With regard to responsive, inclusive, participatory and representative decision-making at all levels (target 16.7), one indicator refers to the proportion of positions held, including by persons with disabilities in public institutions compared to national distribution (16.7.1). In this regard, a very specific measure is the creation of the post of an officer on albinism in the ministry responsible for persons with disabilities or in a national human rights institutional framework. The relevant indicator could provide information on whether there is such a post with a legal basis and sufficient funding, as well as the appointment of a person with albinism to the post.

59. Indicator 16.7.2 measures the proportion of population who believe that decision-making is inclusive and responsive, by sex, age, disability and population group. This indicator could disaggregate data to account for persons with disabilities or by population group and therefore specifically identify the perception and life experience of persons with albinism.

60. Additional specific measures would be relevant in the context of Goal 16 in the case of persons with albinism within refugees or camps for internally displaced persons. Such measures could include: (a) the preparation, through community and family awareness-raising, of communities concerned to receive displaced persons with albinism; and (b) setting up official records of displaced persons with albinism.

[17] Marta Santos Pais, Special Representative of the Secretary-General on Violence against Children, "Shining our light to the world", statement on International Albinism Awareness Day, 13 June 2018. Available at http://bit.ly/2leImtk.

## C. Equality and non-discrimination

### Gender equality

*Relevant Goal*

61. Sustainable Development Goal 5, achieving gender equality and empowering all women and girls, is relevant to women and girls with albinism, who are particularly vulnerable. Target 5.5 seeks to ensure women's full and effective participation and equal opportunities for leadership at all levels of decision-making in political, economic and public life. Specific targets regarding their participation in society are measured through the proportion of seats held by women in national parliaments and local government (indicator 5.5.1) and the proportion of women in managerial positions (indicator 5.5.2). These indicators could be disaggregated in order to collect information on the situation of women with albinism in those areas. A complementary indicator would be the number of countries that have created a post of officer on albinism and appointed a person with albinism to senior public office, disaggregated by gender.

62. Goal 5 also seeks to end all forms of discrimination against all women and girls everywhere (target 5.1), assessing whether legal frameworks are in place to promote, enforce and monitor equality and non-discrimination on the basis of sex (indicator 5.1.1). Data to be collected in this regard could be disaggregated by age, location and disability, including albinism.

63. Target 5.2 seeks to eliminate all forms of violence against women and girls in public and private spheres, including trafficking, sexual and other types of exploitation. While the target is universal in scope, the related indicators narrow the focus on girls 15 years and older who are victims of physical, sexual or psychological violence by intimate partners or sexual violence by others, other than intimate partners. Likewise, target 5.3 concerns the elimination of all harmful practices, such as child, early and forced marriage and female genital mutilation, while its indicators relate only to forced marriage (indicator 5.3.1) and female genital mutilation/cutting (indicator 5.3.2).

*Specific measures*

64. Given that persons with albinism, in particular women and children, are victims of witchcraft-related harmful practices, complementary measures and policies designed to meet the targets of Goal 5 for women and girls with albinism could include the measures outlined below. It is important to note that the same measures could also advance peaceful societies and access to justice.

65. In countries in which attacks are occurring, measures could include: (a) carrying out direct public education on albinism; (b) carrying out public education on albinism in all areas in which attacks have been reported; (c) carrying out innovative public education programmes with high impact and national coverage including through the use of traditional and social media; (d) conducting national needs assessment of persons with albinism in each country, disaggregated by gender, age and health status; (e) keeping accurate documentation and publishing information on every attack and the government actions taken on them; (f) producing one evidence-informed report to identify the root causes of attacks and other human rights violations against persons with albinism; (g) developing a long-term national legal and policy framework, based on evidence-informed research, addressing the root causes of attacks; (h) ensuring full access to police and other security apparatus at the community level; (i) providing security goods to persons with albinism in areas in which attacks occur and to those who have been victims of attacks; (j) reviewing legislative frameworks, including

with regard to trafficking in body parts, witchcraft and traditional medicine, and recognition of colour as a ground of discrimination; and (k) prosecuting all reported cases of attacks and related violations, prosecuting all masterminds of attacks and related violations and providing support services to all victims of attacks and their families based on a long-term legal and policy framework.

**Equal opportunity and reducing inequalities of income**

*Relevant Goal*

66. Goal 10 aims at reducing inequality within and among countries, in particular to empower and promote the social, economic and political inclusion of all, irrespective of any status (target 10.2), which includes disability and colour. The related indicator of progress will measure the proportion of people below 50 per cent of median income, by age, sex and disabilities (indicator 10.2.1). With regard to persons with albinism, the indicator needs to be made visible via disaggregated data in order to give an account of their specific situation and ensure that they are not left behind. The target could be linked to those regarding social protection systems and could go beyond the indicator of income to provide a broader perspective on inequalities disproportionately affecting persons with albinism.

*Specific measures*

67. In addition to the general goal of inclusion in Goal 10, target 10.3, is of central importance to the realization of the pledge to leave no one behind. It seeks to ensure equal opportunity and reduce inequalities of outcome, including by eliminating discriminatory laws, policies and practices and promoting appropriate legislation, policies and action. This target echoes target 16.B, which seeks to promote and enforce non-discriminatory laws and policies for sustainable development. In this regard, specific indicators measuring the number of countries that have adopted related legislation and policies could measure progress towards target 10.3.

**Peaceful and inclusive societies**

*Relevant Goal*

68. Target 16.B to promote peaceful and inclusive societies and reinforce laws and policies for sustainable development, which is to be monitored by the proportion of population reporting discrimination against them on a prohibited ground under international human rights law (indicator 16.B.1), is of relevance. Efforts towards reaching this target could be considered in conjunction with targets addressing all forms of violence namely targets 16.1 and 16.2, considering that violence amounts to an extreme form of discrimination. Moreover, the combination of data on cases of violence, may lead to accumulated information on discrimination that could, in turn, compensate for the limitations inherent to qualitative measures of perceived and actual discrimination, as discussed below.

69. First, the perception of discrimination alone, as encapsulated by target 16.B.1, does not provide robust data on actual discrimination, in particular structural discrimination. This is particularly the case when victims of discrimination tend to be ostracized and live in fear, causing both the loss of self-esteem and self-withdrawal. Ultimately, mere reports of perceived discrimination may undermine the prospects of fully understanding and adequately addressing actual and structural discrimination.

70. Second, indicator 16.B.1 refers to discrimination on the basis of a ground of discrimination prohibited under international human rights law. The indicator should cover multiple and intersecting forms of discrimination to comprehensively and adequately reflect patterns of discrimination informing non-discrimination policies.

In this regard, persons with albinism face intersecting discrimination on the combined grounds of disability and colour and may also be victims of discrimination on other grounds, such as age and gender. In this regard, a complementary specific measure to be taken by Member States could be to develop at least one programme that touches on multiple and intersecting forms of discrimination faced by persons with albinism.

*Specific measures*

71. When considering target 16.B in relation to persons with albinism in countries in which there are records of attacks against them, legislation and policies could be adopted regarding the prohibition of trafficking in body parts, harmful practices related to witchcraft and traditional medicine, the prohibition of discrimination on the basis of colour and the prohibition of discrimination against displaced persons. An additional supplemental indicator that could be considered in the light of target 16.B, is progressive jurisprudence in national, regional and international jurisdictions advancing the cause of reasonable accommodation and non-discrimination for persons with albinism.

72. Furthermore, to measure the progress of the specific measures proposed above, Member States and intergovernmental bodies could consider the number of countries that have adopted and put in place laws and policies prohibiting trafficking in body parts and harmful practices from witchcraft and traditional medicine, as well as prohibition of discrimination on the basis of colour. With regard to jurisprudence, the following information could be collected to measure progress: (a) the number of countries in which a litigation case has been conducted on reasonable accommodation and non-discrimination in national, regional and international jurisdictions; and (b) the number of judicial mechanisms at the regional level that have been made aware of the situation of persons with albinism.

# IV. Good practices and challenges in data collection

73. A lack of data collection and analyses contributes to the marginalization of those whose specific needs or condition remain invisible and ignored. [18] A lack of disaggregated data has been systematically pointed out by treaty bodies as a factor contributing to discrimination. Accordingly, there is an urgent need to build the capacity and methodology within the framework of the Goals, national statistical systems and policies to collect data on persons with albinism. In this regard, national censuses are a central source of disaggregated data.

74. In any context, a human rights-based approach to data collection is required with the appropriate participation of the concerned population or group and/or its legitimate representatives, as well as appropriate safeguards, in particular for data confidentiality, data collection processes with adequate capacity, the upholding of the "do no harm" principle, adequate communication on the purposes of data collection, self-identification considerations and acceptance by the populations or groups concerned. [19]

75. Of utmost priority are confidentiality and data privacy in countries in which attacks and witchcraft-related harmful practices against persons with albinism are occurring. The nature of such information is of acute sensitivity, in particular where it may reveal the whereabouts of victims. High standards of data protection are therefore required. Accordingly, "access to information must be balanced with the

[18] Winkler and Satterthwaite, "Leaving no one behind?", p. 1076.

[19] OHCHR, "A human rights-based approach to data: leaving no one behind in the 2030 Agenda for Sustainable Development", 2018.

rights to privacy and data protection"[20] and informed consent should be obtained from persons with albinism.[21]

## A. National censuses

76. National censuses offer an opportunity to collect data on persons with albinism. Even though only a few instances have been documented to date, there is a methodology to universalize the collection of data on persons with albinism worldwide through the national census. The methodology was created by the Washington Group on Disability Statistics. The Group developed a short, easily administered, set of questions for disaggregating data by disability status, known as the short set, "it consists of a question set for gathering information about limitations in basic activity functioning among national populations. The questions were designed to provide comparable data cross-nationally for populations living in a great variety of cultures with varying economic resources".[22]

77. With regard to target 17.18, on data, monitoring and accountability, the Washington Group concluded that it would require a minor effort to expand capacity for disaggregation. For countries using poor-quality questions on disability, the cost of replacing those questions with the short set would be minimal. Therefore, the objective of enhancing national capacity to gather disaggregated data by disability is not costly and can be attained by all countries, including low-income and middle-income countries.

78. The short set of questions covers important aspects of the condition of albinism, essentially related to impairment. Data collection on persons with albinism can be improved by introducing a specific category for them. Thus, this category can account for those who require reasonable accommodation, health interventions for skin vulnerability to cancer and protection against discrimination based on skin colour and, where relevant, witchcraft-related harmful practices.

79. The national censuses of Namibia and the United Republic of Tanzania are two instances of good practices of collecting data on persons with albinism. Namibia was the first country in Africa to publish data on albinism from its national census, providing information on the prevalence of the condition. The questionnaire used for the census included two questions on disability.[23] The first question asks whether the person has any long-term disability or limitation, to which the person can choose an answer from a provided list, including "no disability", a list of impairments (such as blindness, visual impairment, deafness, hearing difficulties, mutism, speech impairment, physical impairment-upper limbs, physical impairment-lower limbs and mental disability), "autism", "albinism", "other" or "don't know". The second question asks whether the disability represents an obstacle in learning or engaging in economic activities. While the census did not use the Washington Group methodology, the inclusion of the category of albinism has proved to be a good practice, providing the first-ever national identification and assessment of the situation of persons with albinism in Namibia.[24] In the same vein, Kenya has included a question on albinism in its census for 2019.

80. In August 2011, "1204 people with albinism were recorded in Namibia, giving a frequency of 1 in 1755, the highest national frequency recorded via national census

[20] Ibid., p. 16.
[21] Winkler and Satterthwaite, "Leaving no one behind?", pp. 1086–1087.
[22] See https://unstats.un.org/unsd/censuskb20/KnowledgebaseArticle10680.aspx.
[23] See https://nsa.org.na/page/publications.
[24] Namibia, Namibia Statistics Agency, *Namibia 2011 Census: Disability Report* (2016).

in Africa to date".[25] In addition to the overall prevalence, the analysis of data collected through the census can be disaggregated by gender, rural-urban distribution and distribution by region.

81. In the case of the United Republic of Tanzania, the 2012 census included a specific question, under the section on disability, asking whether each listed person had albinism: "Is [ ] an Albino?". Consequently, "the published results provide the most extensive national data set on albinism that has been obtained to date". The census also provides a good example of disaggregation of data by gender, age group as well as rural-urban distribution.

82. The experience of the United Republic of Tanzania also highlights the challenge in effectively accounting for all persons with albinism owing to the limited capacity of the census to reach remote areas. In addition, persons with albinism may have been hidden by their families during the census, probably out of shame and also because of fear as a result of the attacks going on at that time.

83. In the context of the Goals framework, the short set has been recommended by the Statistical Commission for use in the 2030 round of censuses and was recommended by the disability data experts of the Department of Economic and Social Affairs for disaggregating Goal indicators. In this regard, the Washington Group has published a report on the ability of countries to disaggregate indicators by disability,[26] concluding that, with the use of the Washington Group's set of questions, "identifying people with disabilities according to international standards is both feasible and growing" and can be used to "improve the quality of that disaggregation and provide consistency, without imposing any noticeable burden on their current data instruments".[27]

## B. Other sources of data

84. Regarding prioritizing and fast-tracking measures for those left furthest behind, especially in the context of the daily danger faced by many persons with albinism, data are necessary — without delay. Consequently, other methodologies and sources are crucial for collecting data on persons with albinism in the short term.

85. In Zimbabwe, a large-scale survey of albinism in schools was conducted in 1994 and 1995, leading to information on prevalence, disaggregated by sex, rural-urban distribution and level of education. A striking result was the high number of pupils with albinism in Harare compared with the rest of the country. This was notably the case at the secondary level, possibly as a result of migration from the provinces to the capital by older school-age children.[28]

86. Similarly, in 2018, in Nigeria, the Albino Foundation, with the support of the European Union, began a baseline survey on the condition of people with albinism. Also in 2018, the International Organization for Migration is undertaking a situation analysis on the human rights and protection of persons living with albinism from trafficking in persons and discrimination in Mozambique.

[25] Lund and Roberts, "Prevalence and population genetics of albinism", p. 89.

[26] Washington Group on Disability Statistics, "Report of ability of countries to disaggregate SDG indicators by disability", July 2016.

[27] Ibid., p. 3.

[28] Lund and Roberts, "Prevalence and population genetics of albinism", p. 87.

## C. Challenges

87. There are other challenges to be recognized in seeking data about persons with albinism, whether by means of national censuses or other methodologies.

88. Another concern is to avoid stigmatization through national censuses, by using imposed identifiers. Persons with albinism should be directly involved in choosing their own identifiers, as well as choosing multiple identities when relevant. In addition, a lack of understanding of the condition, combined with a history of non-consideration and an absence of advocacy, seems to prevent the inclusion of albinism in censuses or surveys, notably within the framework of disability.

# V. Implementation, review and follow-up

89. The framework for follow-up and review of the 2030 Agenda provides various entry points to ensure that progress is measured regarding the situation of persons with albinism in every country. The follow-up and review process is a three-level process, including the national level, at which Goal progress reviews are undertaken. National voluntary reports are relevant for marginalized groups among the furthest left behind, because they can draw on non-official contributions, including from civil society, the private sector and other stakeholders, including organizations of persons with albinism. National-level progress reviews are very important as they form the bases for regional and global processes. Global reviews will also rely on the list of Goal indicators of global scope, measured through metadata, mostly by United Nations agencies.

## A. National reviews

90. National reviews are State-driven and undertaken voluntarily basis. The reports should be "open, inclusive, participatory and transparent for all people and will support reporting by all relevant stakeholders" (see General Assembly resolution 70/1, para. 74 (d)). This represents an important entry point for collecting data on persons with albinism and also raising awareness about the condition of albinism nationwide.

91. The participation of persons with albinism in national voluntary reviews will not only inform national policies towards the achievement of the Sustainable Development Goals, but will also inform representatives of the international community in the country concerned. In addition, a review that provides sound information on the situation of persons with albinism can facilitate intergovernmental and international efforts towards improving their situation.

## B. Regional and global reviews

92. At the regional level, bodies and mechanisms such as the regional forums on sustainable development, tasked by the United Nations to ensure follow-up and review of the implementation of the 2030 Agenda, provide a platform for peer review and consensus on priorities. They are also a platform for devising key messages based on the region's collective input at the high-level political forum on sustainable development, which is in charge of the annual global review of progress towards the Goals.

93. In the forums, persons with albinism can provide information on their situation in relation to the implementation of the Goals in their respective countries. In the case

of the Africa Regional Forum on Sustainable Development, the themes to be discussed in the yearly global review are open to civil society organizations, academia and research institutions, among others.

## C. Regional Action Plan on Albinism in Africa

94. In sub-Saharan African, the Regional Action Plan on Albinism in Africa (2017-2021) provides a road map for national Governments to ensure that persons with albinism are not left out of efforts to achieve the Goals.

95. The Regional Action Plan includes measures, targets and indicators that are in line with the Goals, some of which have been proposed as specific measures herein. Therefore, the implementation of Plan in Africa will directly contribute to progress towards the relevant Goals.

## D. Global and regional partnerships

96. The implementation of the 2030 Agenda is based on the establishment of multi-stakeholder partnerships that mobilize and share knowledge, expertise, technology and financial resources in all countries, in particular developing countries to promote public, public-private and civil society partnerships (target 17.17). In this regard, the Regional Action Plan on Albinism is supported by a multi-stakeholder platform of organizations active regionally to promote and implement the Plan. The multi-stakeholder partnership is open to new partners and financial support.

97. Globally, there is a growing network of civil society organizations, United Nations agencies and entities and Member States supporting the efforts to ensure the enjoyment of human rights by persons with albinism worldwide. With increased awareness of this issue, a global partnership on persons with albinism may further help the efforts towards the achievement of the 2030 Agenda for all persons with albinism worldwide.

98. In terms of resources to be mobilized nationally, it is fundamental to highlight that low-cost solutions can significantly improve the situation of persons with albinism. For example, the local production of sunscreen in countries with high sun exposure requires seed funding and can become a sustainable economic activity, while also saving lives. Several studies have identified low-cost strategies to ensure reasonable accommodation of visual impairment and skin protection in school.

99. Nevertheless, specific measures on persons with albinism in the context of implementing the Goals require allocation of earmarked funding in national budgets and, in low-income countries, support via international cooperation. Without this, the situation of persons with albinism is likely to remain on the margins in the manner that the central pledge of the 2030 Agenda aims to avoid. In this regard, it is safe to say that, considering the relatively low prevalence rate of persons with albinism, the resources needed would certainly be modest and affordable by most Member States, while the returns on such investment would be invaluable to upholding the human rights of persons with albinism.

# VI. Conclusions and recommendations

100. **The 2030 Agenda has pledged to leave no one behind, beginning with those furthest behind. Persons with albinism, in particular those living in countries where they are under attack, are among the furthest behind in terms of sustainable development and the enjoyment of human rights. Therefore, the**

**implementation of the 2030 Agenda should include persons with albinism among those to be considered first, in particular regarding the Goals on poverty reduction, health, education, decent work and peaceful societies without the threat of violence or attack.**

101. **To this end, the inclusion of specific measures and indicators that are tailored to persons with albinism and incorporated into development policies constitutes an absolute requirement. Moreover, the review and follow-up framework of the 2030 Agenda needs to facilitate the participation of persons with albinism in national, regional and global processes, notably through the elaboration of national voluntary reviews and the building of national systems of disaggregated data collection.**

## A. Member States

102. **The Independent Expert recommends that Member States, as part of their pledge to leave no one behind, beginning with those furthest behind:**

(a) **Adopt a human rights-based approach to data collection and build national capacity to disaggregate data that capture the situation of persons with albinism;**

(b) **Apply, in data collection, the methodology developed by the Washington Group on Disability Statistics, and include a specific question in censuses identifying persons with albinism;**

(c) **Ensure the consultation and participation of persons with albinism in the elaboration of national development plans and policies, in data collection and national voluntary reviews;**

(d) **Adopt development policies towards the attainment of the Goals that include measures tailored to persons with albinism and, where relevant, support the implementation of national action plans on albinism;**

(e) **Ensure, worldwide, that Member States accord priority to persons with albinism and adopt specific measures in efforts to achieve Goals 1, 3, 4, 5, 8, 10 and 16;**

(f) **Ensure that persons with albinism in sub-Saharan Africa, are explicitly considered in efforts to achieve target 5.2, on eliminating the violence against women and all harmful practices, target 10.2, to ensure social, economic and political inclusion regardless of colour and disability, and target 10.3, to eliminate discriminatory laws, policies and practices.**

## B. International community and international organizations

103. **The Independent Expert recommends that the United Nations system, including its agencies, funds and programmes:**

(a) **Assist States and other stakeholders in ensuring data collection on persons with albinism, nationally, regionally and globally, in line with human rights approaches and principles:**

(i) **Assist States and other stakeholders in the adoption and implementation of specific measures on persons with albinism as part of global efforts to achieve the Goals;**

(ii) **Assist Member States in producing disaggregated data, including by providing indexes on persons with albinism;**

(iii) **Ensure that data provided by the United Nations for reporting on the Sustainable Development Goals, targets and related indicators are disaggregated, including with indexes related to persons with albinism;**

(iv) **Provide support to strengthen organizations of persons with albinism and facilitate their participation in Goal processes at the national, regional and global levels, in particular in national voluntary reviews;**

(v) **Develop national and regional inter-agency or multi-stakeholder programmes to support persons with albinism, in particular for the implementation of the Regional Action Plan on Albinism in Africa.**

104. **Regional and subregional intergovernmental organizations should:**

(a) **Place the situation of persons with albinism on the agenda of their organs and mechanisms;**

(b) **Provide support to States in their efforts to achieve the relevant Goals in relation to persons with albinism by promoting the adoption of specific measures and indicators.**

105. **Development agencies, including the World Bank, regional development banks, bilateral agencies and non-governmental organizations, should:**

(a) **Develop specific programmes to support persons with albinism or integrate albinism into their work;**

(b) **Support States in providing disaggregated Goals-related data on persons with albinism;**

(c) **Provide technical and financial support for Goals-related programmes and policies focusing on persons with albinism;**

(d) **Engage with and support global, regional and national partnerships to support persons with albinism, in particular through the Regional Action Plan on Albinism in Africa.**

106. **Organizations of persons with albinism should engage with the Goals processes nationally, regionally and globally.**

107. **Academic institutions and research organizations should undertake research on the implementation of the Goals in relation to persons with albinism, in particular on data collection and monitoring progress.**

108. **National human rights institutions should:**

(a) **Monitor national data collection on progress towards achieving the Goals and ensure that they are following a human rights-based approach;**

(b) **Address human rights issues faced by persons with albinism in their countries, starting by conducting national studies that inform Goals-related processes;**

(c) **Provide support to persons with albinism in engaging with human rights mechanisms and processes related to the Goals.**